Developing the DMH Research Agenda – Stakeholder Focus Groups

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Executive Summary

The Massachusetts Department of Mental Health provides funding to two Centers of Excellence (COEs) that engage in research related to mental illnesses and mental health services. Other organizations throughout the Commonwealth carry out behavioral health research projects that are supported by various federal agencies and/or private sources. Although much of this research is intended to lead to improvements in the care that individuals with mental illnesses receive, there has traditionally been little communication between the researchers and other stakeholders, such as consumers, Massachusetts-based mental health community service providers, and advocates for persons with psychiatric disabilities.

In an effort to determine the recommendations of stakeholders regarding priorities for DMH research funding, the DMH Deputy Commissioner of Clinical and Professional Services asked DMA Health Strategies and Consumer Quality Initiatives, Inc., to conduct a series of focus groups as well as a thorough review of recent mental health related research studies and current Web sites. Adult focus groups included consumers; transition-aged youth; parents of child consumers; and providers who participated in a total of seven focus groups. In addition, conversations were held with researchers at the two COEs.

The most important research topics for these consumers were:

- Employment (by far the highest priority);
- Housing;
- Communication between clients and providers;
- Alternatives to psychiatric services, especially peer support;
- Access to care;
- Physical health (wellness);
- Stigma (public education) and
- Criminal justice, especially for transitional-aged youth (TAY).

In addition, some consumers would like to see more research regarding multicultural issues, emergency services (especially TAY) and transportation supports.

The parents of youth with mental health needs expressed particular interest in research on:

- Safety (child and parent);
- Support and education for parents;
- Schools; and
- System fragmentation.
- Diagnosis confusion;
- Education and training of professionals;
- Emergency services and the ER; and
- Stigma.

Some parents also expressed interest in the legal system (e.g., DYS); adoptive and foster parents; as well as multicultural issues.

The providers were frustrated that their services were not deriving benefits from ongoing Massachusetts-based research. They also thought it was important for ongoing research and evaluation to be conducted in the course of the dramatic transformations being implemented throughout the public mental health system.

Although providers and consumers are eager to learn about the results of research that can directly influence policy and practice, they perceive a considerable disconnection between research on the one hand and policy and practice on the other. In fact, this study has revealed two levels of disconnection: 1), in the realm of research ideas, between the research that is being conducted and the areas of interest stakeholders express; and 2), in the realm of ongoing communications between mental health researchers and the many other stakeholders in the mental health community. The consensus is that, although the Commonwealth supports extensive mental health research, the results of that research have not been translated into easily identified improvements in practice or changes in policy.

Providers and consumers expressed considerable frustration that they play a minimal role at best in setting the research agenda, and often never learn the results of research that is being done. Focus group participants believe strongly that DMH supported studies should relate directly to issues "on the ground" in the Commonwealth. This idea takes on particular significance now, as the state is in the process of dramatically changing much of the mental health service system – including restructuring both the adult and child systems of care, through Community-Based Flexible Supports and the Children's Behavioral Health Initiative respectively, and reprocurement of the Emergency Service system with new requirements. These potentially transformative changes merit careful study so that the state can evaluate and communicate their impacts on policy makers, providers, consumers and family members, and learn whether they require modification.

Recommendations

The following recommendations to DMH emerge from this study:

1. Research results need to be more widely disseminated to stakeholders on a routine basis.
2. Periodic facilitated discussions should take place among researchers and providers, and among researchers and consumers.
3. Facilitating communication should be viewed as a system-wide responsibility, shared by researchers, consumers, advocates, and providers.
4. The COEs might consider studying important topics that they do not now work on, especially those related to the major changes that the Massachusetts mental health system is confronting.
5. DMH should play a more active role in defining the research agendas of the COEs. Because it already requires that they more widely disseminate their findings within the state, it should review the methodology provided by each COE (especially the UMASS CMHSR "Mental Health Agency Research Network") to determine how to more effectively support these initiatives.
6. DMH could also request that each COE submit an action plan that addresses the interests of stakeholders as determined in the focus groups described in this report. Although each COE is required to have a Consumer Advisory Council, we recommend that the action plan should describe how the COE will engage stakeholders in shaping researchers' priorities and participating in selected grant applications.
7. DMH might spread the responsibility for following research more broadly within the agency by involving, for example, medical directors and others. The Excel charts developed for this report could be shared with appropriate DMH staff, enabling the Department to determine who might want to serve as the lead for each topic; and those individuals could meet with key researchers.

Introduction

The Massachusetts Department of Mental Health currently funds two Centers of Excellence (COEs) that engage in research related to mental illnesses and services: the Beth Israel Deaconess Commonwealth Research Center and the UMASS Center for Mental Health Services Research. *(See page 34 for additional information)* In addition, many organizations and academic centers throughout the Commonwealth carry out research projects that are supported by various federal agencies and/or private sources. Much of this research is intended to lead to improvements in the care that individuals with mental illnesses receive. At the same time, DMH and Medicaid fund dozens of provider organizations that serve individuals who experience mental illnesses. Providers are eager to know more about which services best support improvement, care and recovery. Finally, the voices of consumers and parents merit attention from both researchers and providers. Thus, one of the goals of this report is to inform researchers about providers' and consumers' concerns, and providers and consumers about the research that is being conducted state-wide.

The Department's Deputy Commissioner of Clinical and Professional Services contacted DMA Health Strategies and Consumer Quality Initiatives, Inc., to discuss a methodology to determine the recommendations of stakeholders regarding priorities for DMH research support. Following a few joint planning sessions, the project's goals, objectives, and methodology were decided. DMA Health Strategies and Consumer Quality Initiatives, Inc., conducted a series of focus groups as well as a review of recent documents and current Web sites. Adult consumers in Western, Central and Eastern Massachusetts; transition aged youth; parents of child consumers; and providers attended a total of seven focus groups. In addition, conversations were held with the researchers at the two COEs. This report summarizes the results of those sessions. Additionally, the report provides an overview of current mental health research being done in Massachusetts by other researchers, and the relationship between that research and the priorities of stakeholders; and offers some conclusions and recommendations regarding both priorities for mental health research in the Commonwealth and mechanisms for sharing research findings among all the stakeholders in the entire system.

Methods

DMA Health Strategies (DMA) and Consumer Quality Initiatives (CQI) conducted a series of seven focus groups with stakeholders to learn about their research priorities. The original plan called for one group specifically for transition age youth (TAY), another three for adult consumers, one for parents of youth, one for family members of adults and one for providers. We held the groups for transition age youth and adult consumers, as well as two groups with parents of youth and one group with providers. However, although we made every effort to hold a group for family members, we were unable to do so within the required time frame.

In addition to holding this series of focus groups, we reviewed much of the mental health research that is being done in Massachusetts' colleges, universities, and medical centers, and held discussions with researchers at the two DMH supported COEs.

Recruitment

CQI reached out to a variety of organizations for assistance in recruiting stakeholders for the focus groups and developed a flyer that was sent out to the contact person for each organization. We did not pay a stipend for attendance, but did serve refreshments.

For adults, we made arrangements through the Recovery Learning Communities in Worcester and Holyoke, the Transformation Center in Boston, and the Statewide Young Adult Advisory Committee. We had good attendance at all of the adult groups, with a total of 46 participants.

For family members of adults, we were in touch with NAMI-Mass. They distributed our materials through their *listserv* and we scheduled a focus group for a Saturday morning. We cancelled this session a few days in advance because no one had registered to attend.

For parents of youth, we contacted the Parent/Professional Advisory League (PAL), and they suggested that we talk to their affiliates. We reached out to the parent support group at Wayside Youth and Family Support Network in Framingham and then held a group with three parents.

We also contacted the Massachusetts Behavioral Health Partnership (MBHP) family advisory council (FAC), whose membership includes both parents of youth and family members of adults. We scheduled a time to hold two separate focus groups during part of an FAC meeting, and attended with two facilitators and two note takers. However, in the event we decided to hold just one group because all of the individuals present were parents of youth.

Focus Group Process

CQI's executive director, Jonathan Delman, facilitated five of the focus groups with consumers and family members, and Melissa Goodman, CQI's director of operations, facilitated the sixth. Richard Dougherty and Jonathan Delman facilitated the discussion with providers. For each group, CQI staff took notes on a poster board and on notepads. We developed guidelines for facilitators of the focus groups, which can be found in Appendix I.

In order to ground participants in the elements, purpose and value of research, the facilitator engaged in a staged introductory process.

First, the facilitator explained research as: "the planned [systematic] process of collecting and analyzing information to increase our understanding of a topic under study." S/he described some of the variety of kinds of research, from randomized controlled trials to focus groups to literature reviews. Participants were asked to provide examples of research, and the facilitator suggested some examples as well.

Second, s/he explained the level of investment of DMH in mental health research, including its funding of two Centers of Excellence that are part of the University of Massachusetts Department. of Psychiatry and the Beth Israel/Deaconess Department of Psychiatry.. S/he also described the ways in which researchers decide which topics to research, with various levels of community input. In addition, s/he gave an example of how research in Massachusetts has directly affected mental health services and/or policy.

We took a segmented approach to eliciting the group's research ideas. We first asked: "What are some of the major concerns faced by people with serious mental health conditions (e.g., DMH clients) in Massachusetts?" We offered each person a chance to respond. Then we opened the question up for discussion. We took notes on poster board. This part of the process took about 45 minutes. Then we had the group take a 10 minute break, during which CQI staff reviewed the poster board and notepad notes and identified themes based on the content and enthusiasm of the group's comments. We then placed those themes on a single sheet of paper and asked participants if these were their priority research themes. Group members answered in the affirmative, sometimes offering a few minor adjustments. After that, we chose some of the more popular themes and worked with the group to develop and hone their research ideas and questions. Each group lasted for about 90 minutes, with a 10 to 15 minute break in the middle. The average number of participants per group was 12.

Analysis

As each focus group proceeded, and directly thereafter, the facilitator and recorder made an effort to reach a preliminary agreement on the research priority categories, or themes, for the group. As part of that process, we ranked categories according to the group's level of interest, which was determined by the number of participants expressing interest in the topic and the degree of enthusiasm they indicated for it.

After returning to the office from the focus groups, we entered both poster board and paper notes electronically, and they were reviewed by at least one other CQI staff member. After reviewing those notes and the strength of the themes, we sometimes collapsed similar categories and broke other categories into two new ones. We prepared a summary of people's comments within each category.

We then looked at all of the focus group findings together. With regard to the four consumer groups, we created a grid that allowed us to determine both 1) how frequently a topic came up, and 2) the intensity of discussion around that topic in each group. We analyzed the findings of the four groups collectively based on that grid and our original notes. We conducted the same process for the two focus groups held with parents of youth. Because there was only one provider focus group, we reviewed and analyzed those results separately.

Results of Focus Group Discussions

In this section, we will summarize the results of the focus groups, first reviewing the adult consumer groups, then the TAY group, the parent group and finally the provider group. While each group, as anticipated, suggested its own research priorities, there were some common themes across the groups. In analyzing the results, we have attempted not just to summarize what participants said in the focus groups but also to document the degree of intensity with which they said it.

Adult Consumers

Introduction

CQI held four research priority focus groups for adult consumers, including one exclusively for transition age youth which is also discussed separately. These adult groups took place as follows:

Eastern Massachusetts focus group, February 11, 2009
Transformation Center, Roxbury, MA
15 participants
10 female, 5 male
10 White/Caucasian, 4 African America, 1 Asian

Western Massachusetts focus group, February 2, 2009
Western Mass. Recovery Learning Community, Holyoke, MA
13 participants
9 females, 4 males
10 White/Caucasian, 2 African American,
3 with mobility issues, 1 deaf

Central Massachusetts focus group, February 23, 2009
Central Mass. Recovery Learning Community, Worcester, MA
6 participants
3 females, 3 males
All White/Caucasian

Transition Age Youth (statewide), February 17, 2009
Tatnuck Booksellers, Westborough, MA 01581
12 young adults
7 females, 5 males
4 African American, 8 White/Caucasian

Total:
46 Participants
29 females, 17 males
34 Whites, 10 African Americans
(We did not track Hispanic ethnicity)

Research Priority Themes

These groups were typically most interested in services and supports available (or not) to consumers, while much of the research being conducted in Massachusetts, particularly at the medical centers, with the exception of the UMMS CMHSR, is related to drugs, neuroscience and/or diagnoses.

The themes across these groups can be classified into three tiers according to the according to number of groups that mentioned the issue and the importance attached to them by focus group participants. Employment was the only theme in Tier 1; that is, it was mentioned in all four groups and strongly in two. Below is a list of the tiers and significant themes:

Tier 1 Employment
Tier 2 Housing
Client-provider communications
Alternatives to psychiatric services, including peer support
Access to care

Physical health (wellness)
Stigma (public education)
Criminal justice

Tier 3 Multicultural
Emergency services (addressed in TAY)
Transportation.

The Tier 1 and 2 themes can be broken down further into three major categories (see grid):

1. Themes addressed in all four groups (all except "employment" without intensity in any one group)
2. Themes addressed in all three of the "older adults" groups (not in TAY),
3. Themes addressed in the Transition Age Youth group and 2 of the adult groups.

The table below provides further detail on the themes. The "plus" signs next to some themes signify the number of groups in which the theme was emphasized with great enthusiasm by most of the group. Thus, the tiers were developed on the basis of the "plus" signs associated with each theme. The table also includes, under each theme, research institutions and/or specific researchers that to our knowledge are conducting research in that area. It is important to note that this list represents the results of a thorough search of university, medical center and public agency research, but does not cover private research organizations such as CQI.

Table 1

For further detail, see the table included in Appendix 5.

Group	**Theme**	**Ongoing Research in Massachusetts**
All four groups	Employment++	There is a significant amount of vocational research in Massachusetts, but not concentrated at any one research center.
	Housing	There is very little research in this area.
	Client-provider communications, informed consent	There is some research in this area, but not very much.
All three Older adult groups	Alternatives to psych/med care (Peer services, crisis hostels)+++	This is a broad area, and there is a variety of research in Massachusetts. A primary focus for some is the role of peer specialists. Others are looking at support groups, trauma care, computer-assisted treatment, and alternatives to medications such as fish oil.
	Access to care (insurance, managed care and related issues)++	There is a fair amount of research in this area.
	Physical health, wellness++	There is a significant amount of research in Massachusetts in this area. Key areas include smoking cessation and delivery of mental health care in primary care settings.
2 Adult groups and the TAY group	Criminal justice, forensics+++	There has been quite a bit of research in this area, largely based at the University of Massachusetts Dept. of Psychiatry.
	Stigma, education for all+	There has been some research in this area.
+ Number of groups in which the theme was emphasized.		

Below is a more detailed discussion of the themes. Note that this section focuses on the concerns of the "older" adults, and only mentions concerns of transition age youth (TAY) peripherally. For more detail on TAY, see the following section.

Tier 1

Employment (education) - People consistently expressed interest in research on vocational supports and working. There were many reasons for this concern, but one was the recent loss of the DMH funded programs dedicated to Supported Employment and Education. The most important research question seemed to be:

- What kind of vocational supports and settings are most effective for each relevant group of people (e.g., by vocational interest, culture)?

Other research questions included:

- How does having (or losing) vocational supports or a job impact a person's recovery process?
- What is the effect of a criminal record on work success? What are the best interventions to improve work success for people with criminal records?
- What is the impact of the MCAS exam on students with mental health disabilities (e.g., are they encouraged to drop out; are they "coached" to pass?)?

Tier 2

Housing - Consumers' primary concerns are availability, affordability and quality, as well as homelessness. They suggested the following research questions:

- What is the best way to decide whether someone is ready for more independent housing?
- What outcomes should we use to measure the success of independent living?
- What is the effectiveness of transitional group homes on sustainable independent living?
- What are the most effective ways to get homeless people into housing?
- Are people being placed in the appropriate level of support/supervision? What is the impact of an inappropriate placement?
- How do mixed environments (e.g., with people with other disabilities or with non-disabled) compare to peer environments regarding community integration?
- What is high quality affordable housing for people with mental illness?

Client-Provider communications, Informed decision making - In all groups, participants felt it was important for clinicians to provide information about treatments and alternatives, and to listen to and respect clients' wishes. Specific research questions included:

- What is the impact of informed consent and crisis planning on recovery outcomes (e.g., empowerment)?
- What is the impact of Rogers Orders on recovery outcomes?
- How do clinicians understand "dignity of risk," and do they take it into account when working with clients?

- How many peers have medical and psychiatric advanced directives in Massachusetts? For those who do not have them, why not?
- To what degree do psychiatrists respect clients' wishes contained in advanced directives?

Alternatives to psychiatric care - "Alternatives" here consisted of a wide variety of services or supports, including (but not limited to):

- Peer Specialist Services
- Peer support/education groups
- Peer-run crisis respite (trauma-informed)
- Respite
- Exercise
- Reiki
- Yoga
- Acupuncture
- Mindfulness
- The role of spirituality in diagnosis and treatment
- Art

Research questions included:

- What is the effectiveness of different alternative treatments and what outcomes do they produce (e.g., reductions in anxiety or trauma)?
- Does it matter who "provides" or "leads" the alternative or holistic treatment/practice, e.g., peer, staff, community members?
- Do providers ask about trauma (why… why not)? Are ACE (Adverse Childhood Experience) scores assessed for people with mental health conditions in Massachusetts? How might those scores be used?
- Does it make sense to integrate traditional and non-traditional services, and if so, how?
- What models of trauma-specific and trauma-informed peer directed respite programs are most effective (what would they look like to consumers/survivors?)?

In one group, participants identified four different types of peers working in services:

1. Peer Specialists
2. Certified Peer Specialists
3. Peer group leaders
4. Peer Clinicians

Research questions in that regard included:

- How does the peer's use of lived experience affect outcomes?
- What conditions need to be in place for a peer worker to succeed in the clinical workplace?
- How does working as a peer specialist impact a person's recovery/growth? What are the differences among the types of peer workers?
- What are the differential characteristics of consumers in the mental health system who have contact with peer support and those who do not?

Access to services for disenfranchised groups ("falling through the cracks") - Participants were vigorous in their statements of concern for people with mental illness who were either not getting any services or were underserved. They discussed their worries about some people who "fall through the cracks," and described them within these categories:

- Demographic
  - Homeless
  - Racial/ethnic minority group (e.g., African American)
  - Other kind of disability (e.g., deaf)
  - Elderly
- DMH-related
  - Not eligible for DMH services but could use a referral
  - Eligible for DMH services, but services not available
  - Eligible for DMH services, but do not have a case manager
- Non DMH related:
  - Not eligible for services from any public entity: autism spectrum disorders

A repeated research idea regarded to what degree consumers' mental health needs are not being met. Additional research questions include:

- What have been the effects of budget cuts (e.g., loss of case managers) on access to care for these groups? How have outcomes been affected?
- How will changing to a flexible support model affect access to care, continuing care, and outcomes for these groups?
- What resources are used by people who lack access to the health care system? (e.g., transitional assistance programs, homeless centers).
- What are effective strategies for community outreach to people who are, for example, homeless and on park benches?
- Who are the people who have left the system, and why?
- Why do some ethnic and racial minorities not go to treatment?
- What is the experience of people who have successfully accessed services after a long time of not accessing services (or being able to do so)?

There were also discussions about the effect of insurance and the cost of care on access to care. Research questions here included:

- What is the impact on access to and quality of services when the costs of insurance and medications increase?
- What impact has Massachusetts healthcare reform had on the well-being of mental health consumers?
- Does self-directed care improve access when compared to the medical necessity model of insurance?

Physical health and wellness - Consumers expressed interest in research on the following topics related to physical health and wellness:

- Polypharmacy and its effect(s) on health in children and adults;
- Integration of physical and mental health care;

- Role of primary care;
- Needs of people with physical disabilities;
- Why mental health consumers die younger;
- Improving physical health and wellness issues; and
- Addressing "bad habits" (e.g., smoking).

They also had some specific research questions:

- How many consumers are affected by polypharmacy, and what are the results?
- Is a reduction in use of psychotropic medications correlated with improved physical health?
- What has been done in other states to reduce behavioral health polypharmacy?
- What are elements of an effective smoking cessation program – what helps peers stop smoking?
- What is the impact of the integration of mental health and physical health on people's physical and mental health? (There was particular concern for people with physical disabilities). Are PACT teams helping people improve their physical health? (PACT teams as an example of integrated physical and medical health care)
- How will DMH's flexible supports model work to improve people's physical health and wellness?
- How can the primary care physician most effectively improve the health of people with mental illness?
- What are the best ways to address the early death rates among mental health consumers?
- How do exercise and nutrition programs affect health and reduce the premature death rate?
- How do outcomes differ between people attempting to engage in social/physical health activities alone versus those who engage in those activities in groups?

Criminal justice system (prison and court system involvement) - Participants were very interested in research about how consumers interact with the criminal justice system, including prisons, police, and courts. In particular, they were concerned about the effects on people's lives of having criminal records and the impact of jail diversion programs and mental health courts. Specific research questions included:

- What is the impact (e.g., on recidivism) and cost effectiveness of jail diversion for a person who has committed a non-violent crime?
- What is the effectiveness of rehabilitation services in jail?
- What is the quality of mental health services for consumers who have significant amounts of criminal involvement?
- How many and which people with criminal records are able have successful job, housing and other community integration outcomes?
- What is/will be the impact on consumers of changes in CORI regulation?
- What are the outcomes of consumers who are adjudicated in mental health courts as opposed to those who are adjudicated in regular courts? What is the experience of people who participate in mental health courts? How effective are mental health courts at keeping people out of jail in the long term?

Stigma, education - Participants were very aware of the stigma existing in society. Their research questions were focused on things they could do to reduce stigma. They were interested in studying the effectiveness of the following in reducing stigma:

- Disclosing mental illness to others (particularly after knowing them for a time) and
- Telling their recovery story.

Consumers' Research Priorities in Relation to Existing Research

With regard to the research priorities of adult consumers, the general topics that are receiving the **most** attention from researchers in Massachusetts are:

- Alternatives to standard treatment, including peer support
- Physical health/Wellness
- Client-provider communications
- Multicultural issues (a low priority overall among focus group participants)

Priority topics receiving the **least** research attention in Massachusetts are:

- Education and training of professionals (e.g., in provider agencies)
- Housing
- Emergency Services

With regard to the studies approved by the DMH IRB:

- A large majority focus on specific diagnoses (most commonly schizophrenia and the first episode of psychosis)
- Over one-third focus on medication
- Between 10% and 20% focus on cognition, child/family, health promotion and/or treatment models

Transition Age Youth (TAY)

Twelve young adults, aged 18 to 27, participated in the statewide TAY focus group, which was held as part of a statewide monthly TAY meeting at Tatnuck Booksellers in Westborough. Participants included seven females and five males; four were African American. Participants came from throughout the state, and a few were current state hospital patients. All participants received transportation to the meeting from a case manager or other staff person. These young people shared concerns about stigma; vocational and educational services and supports; criminal offense records; interactions with the criminal justice system; use of emergency room and crisis services; and housing.

This group of TAY was especially eager to see research that would assess the effectiveness of training and education programs geared to improving staff competence at working with young adults. Believing that staff does not appreciate the unique qualities of each individual, they would like to see research about:

- Empathy training and "hearing voices" training for staff;
- Basic didactic education on mental illness;
- How to correct the misconceptions of the general public regarding mental illness, while sensitizing the public to the seriousness of mental health issues;
- How to educate individuals who work in criminal justice about mental health issues; and
- How all of these trainings are best implemented.

These young adults were also very much interested in research related to vocational issues. Because employment is important to them, they would like to see studies of:

- Best practices in the areas of creating a culture of inclusion in the workplace;
- Implementing reasonable accommodations; and
- The impact of disclosing mental illness on success in the workplace.

Their concern about education led them to an interest in research on:

- The cost-effectiveness of programs such as TRIO (a federal program designed to support students from disadvantaged backgrounds in gaining admittance to and stay in college).
- How post-secondary educational institutions see their responsibilities to help people with mental illness achieve their educational goals;
- The difference in college admissions between having a GED and having a high school diploma.
- The impact of what they consider the discriminatory care they receive when they are in crisis, and how to reduce those practices.

Finally, this group of TAY would be eager to see research into a variety of housing issues, including:

- Approaches to helping homeless young adults obtain housing; and
- Helping young people meet non-financial requirements such as attending meetings (especially with landlords) on time.

Parents of Youth

CQI conducted two focus groups with parents of youth who have serious emotional disturbances. Three women attended the first group and seven women attended the second. All were White/ Caucasian. Thus the group was fairly homogeneous and typical of those who tend to be active in advisory boards and support groups; we recognize that the groups' thoughts may not reflect the needs and concerns of other ethnic communities.

The research interests the participants identified fell into ten major categories. The group's comments, summarized by category below, are followed by the research questions related to that category. Research topics that were addressed with great interested by many or all in the groups were: safety (child and parent); support and education for parents; schools; and system fragmentation. Topics addressed with interest by many or all in the groups were: diagnosis confusion; education and training of professionals; emergency services and the ER; and stigma. Topics addressed by some in the group were the legal system (e.g., DYS); adoptive and foster parents; and cultural issues.

Safety – Child and Family - Participants noted several safety issues of major concern to them.

- First, they are concerned about the overall safety of their children with mental illness.
- They are concerned about the safety of their other children and family members when their child with SED is escalating. They expressed a need for more training in de-escalation skills that will help them protect their children and family members at home.

- They also raised the issue of safety for their children in the school system, where they are vulnerable to bullying and victimization, and are stigmatized by both classmates and school personnel.

Support and Education for Parents - Participants discussed their ongoing need for support in parenting children with mental illness.

- They need support when their children are first diagnosed and they feel lost and alone.
- They want support and education to guide them in making appropriate treatment choices and in finding the best treatment for their children. Many have found that the peer-to-peer support and information they have received from other parents (e.g., parent partners) have been the most valuable to them.

Research questions include:

- Does broader integration/use of Parent Partners help other professionals understand parents better?
- Are Parent Partners accepted in the agencies and venues where they are established?
- Do the traditional professions use them and learn from them?

Support from peers and professionals is critical to their ability to accept their children's mental health diagnosis and then to navigate the world of mental health services successfully. Parents suggested that they need ongoing support as they make decisions about treatment, schooling, and other issues for their children with SED. Participants expressed concern about the dearth of educational resources for families about SED in children and the best treatments available. They also expressed a need for more education at the point of diagnosis and treatment initiation so that they can understand their options and make good decisions and choices. In sum, they felt a need for research on the most effective approaches to providing decision support to parents.

Parents also identified the following research question:

- Why is it that some support groups for parents are very successful and others struggle with attendance and interest? How are parents successfully engaged in support groups?

Schools - Participants conveyed many concerns about how their children are understood and handled by school personnel. It is their experience that school personnel in general – from principals and teachers to other staff and bus drivers – do not understand the behaviors associated with SED in children. Thus they often misinterpret the behavior the children exhibit when they are escalating and handle it as if it were a discipline issue. This is an area where families believe an extensive educational effort should be made so that school personnel at all levels understand the signs, symptoms and behavior associated with SED in youth and are familiar with effective interventions to use when a child is in difficulty.

The participants described schools as "not safe" and "crisis zones" for their children. The lack of understanding of mental illness on the part of administrators, teachers, social workers and staff filters down to the student population so that children with SED are stigmatized, bullied and blamed. School becomes an unsafe and miserable place to be which can then affect a child's

educational achievement and desire to stay in school. Parents believe there is a "drop-out" crisis among children with mental health issues.

Participants have found that some schools are filing charges against children with mental health issues for certain behaviors because they don't understand those behaviors or know what else to do. Participants encounter resistance at all levels of the education system to open dialogue, education about SED, and consideration of alternative interventions for problem behaviors. This system-wide opposition to change is difficult for individual parents to address. Research questions raised include:

- Do teachers who receive education about mental health issues in children behave differently?
- What are the best ways to help school administrators and staff understand the needs and behaviors of children with SED?

Systems Issues- Fragmentation - Several systems issues are of particular concern to parents. The lack of integration among service systems involved with youth - education, mental health, physical health, criminal justice – presents significant roadblocks to sharing information and adopting a unified plan for a child. Participants also noted a pervasive resistance in the community to understanding the behavior and mental health needs of children with SED. Resistance to change or knowledge among staff and professionals presents particular challenges to parents who are trying to obtain appropriate treatment and care for their individual children.

The lack of service system integration also leads to fragmented information – there is no one place for parents to go to learn about their child's condition and available supports. The information that they are able to obtain usually is segmented according to the system supplying the information so parents must figure out on their own, or with the help of other parents, how to integrate what they know across systems. An additional system issue is the manner in which mental health care is paid for and structured, so that there are no incentives for healthcare systems to engage in approaches that consider and include families in the treatment plan and procedures. An exception to this is the new Children's Behavioral Health Initiative (CBHI), which systematically includes families and natural community supports.

One research question was:

- What policy or other system changes would improve integration of systems and services for children with mental illness?

Diagnosis confusion - These parents believed that many different diagnoses are used for the same set of behaviors or psychiatric symptoms. This is misleading to parents who discover that their child gets a different diagnosis with different practitioners. Participants said that they did not know how to deal with this confusion. As a result, they end up mistrusting the mental health professionals who are supposed to be helping them.

- Participants wanted to see more research on the reliability and "validity" of various diagnostic terms, and on how to encourage diagnostic consistency among professionals.
- Parents are also interested in research that may uncover reasons why practitioners, particularly child psychiatrists, have so much diagnostic variability for the same individual.

Training and Education for Professionals - Participants expressed much concern about what they perceive to be poor preparation of professionals (e.g., DCF workers, pediatricians, RNs) who care for youth with SED. They have found that juvenile justice, social service (DCF) and physical health professionals are generally not knowledgeable about the symptoms, behaviors, and effective treatments associated with SED.

- They wanted to see an assessment of various professionals' knowledge of youth mental health issues.
- They were also interested in research on effective education methods to train professionals on the mental health needs of children.

Professionals' lack of understanding of, and unfounded assumptions about, mental illness in youth can lead to inappropriate treatment in a variety of settings: schools, ERs, mental health agencies, police stations. This leads to escalation, stigma, and ineffective interventions that leave youth and family traumatized. Participants again expressed a need to have mental health professionals who can provide family-focused treatment to the entire family. They felt that family partners could be helpful in influencing professionals, just as they can be helpful in educating parents. Research questions include:

- What is the impact of Family Partners on organizational operations?
- How can organizational staff best be educated on the role of the Family Partner?
- Does staff education influence how family partners are used/integrated?
- What are expectations and evaluation plans for CBHI regarding family partners?

Emergency Services and the ER - Participants have found that hospital emergency rooms are generally insensitive to the treatment and crisis needs of children and adults with SED and mental health issues, leading to discomfort and needs not being addressed. Participants reported that they need support and guidance on next steps when the child is seen in the ER, is not admitted for 24-hour care, but cannot go home. One specific research question was:

- **How will the new ESP model improve care for youth?**

Stigma - When children with SED participate in community activities, they experience some of the same stigma and misunderstanding they face at school. Once again, participants pointed out the need for education and training in mental health issues/behavior/management for staff of community sites serving children. (Their children feel as though they stand out, and may be less likely to know other youth.).They wanted to see research on:

- The effect of mentors on youth participation in community activities;
- The ways in which youth want to participate in public education; and
- The effect of participation on their confidence.

Legal System, DYS - Participants noted that all legal system/DYS staff who have contact with children should be educated about mental illness related issues and effective interaction techniques. Their concern is that legal system practices tend to escalate and exacerbate mental health conditions. When children with SED are held in DYS custody, they may be prevented from getting and taking their psychiatric medications for up to several days. (In fact, some policies in the legal system

endorse withholding medications when children are first taken into custody.) They were interested in research on:

- The effect of youths' contact with the legal system and DYS.

Adoptive and Foster Parents - As with other families, parents who adopt or foster children with SED need support and training so that they can understand the behavior and mental health needs of those children. Participants commented that DCF workers need adequate education on mental health issues so that they can be part of the support system for foster and adoptive parents. They were interested in how mental health treatment of adoptive/foster youth with SED compares to treatment of other youth with SED.

Cultural Issues - Participants noted that families from different cultures handle behavioral and mental health issues differently. They were interested in research on this topic.

Providers

One focus group was held with providers on June 3, 2009, at the office of Mental Health and Substance Abuse Corporations of Massachusetts in Natick. Six large provider organizations were represented. The primary question presented for discussion was: Should the department of Mental Health have a role in research? If so, what should that role be?

There was some discussion of the two Centers of Excellence (also referred to as Commonwealth Research Centers), one at Beth Israel Deaconess Medical Center in Boston and one at the University of Massachusetts Medical School in Worcester. Both receive funding from the Department of Mental Health. In the past few years, through the Deputy Commissioner of Clinical and Professional Services's Office, DMH has been an active contract manager, asking questions such as: Why are we doing this research? Does it have significant implications for our service provision system? Providers have a hard time distinguishing between the two COEs and do not know much about what they are doing and what they specialize in. The group mentioned the importance of provider-based research and expressed hope that communication between the designated research COEs and the provider communities can be enhanced and expanded.

Current Provider-Based Research

Individual participants described their agencies and the research they have been conducting.

The Bridge of Central Massachusetts is conducting two main research projects, both of which were internally generated.

- The first, with Leonard Doerfler of Assumption College, is an on-going evaluation of the use of Dialectical Behavior Therapy with transition-age youth. They measure such variables as the number of hospitalizations; the number of days in the hospital; their functioning pre-, during, and six months after hospitalization; suicidal behavior; and non-suicidal self-injury.
- The second project, also on-going, measures illness management and recovery among adults.

Community Healthlink has been involved in clinical trials with the UMass faculty that were funded by the National Institutes of Health and a drug company. Also, they have conducted

program evaluations of SAMHSA grants. Both of these endeavors are in collaboration with the UMMS CMHSR.

NFI described participating in national projects studying multi-systemic therapy (MST) and wraparound. They worked with BUCPR on a review of the effectiveness of WRAP.

Community Counseling of Bristol County has engaged in research on elder outreach with UMass CHPR.

Vinfen described a number of internally funded, IRB-approved projects:

- Emotional intelligence and the use of computers with people with psychiatric disabilities (with the BI/Deaconess CRC);
- A rating system for outcomes of recovery and milestones of recovery;
- Large randomized controlled studies of health and fitness with people with psychiatric disabilities;
- Helping individuals with co-morbidities to manage their health;
- Smoking cessation; and
- Studies involving the first episode of serious mental illness and its effects (with the BI/Deaconess CRC).

A Provider Research Agenda

These providers urged that researchers focus on areas such as the following, keeping in mind the over-arching purpose of determining the most efficient use of public dollars:

- Psychosocial rehabilitation.
- The Children's Behavioral Health Initiative (CBHI), an enormous program which should be subject to research. There is mandatory screening for mental health issues; someone should be looking at the results.
- Youth transitioning to adulthood.
- In children's services, the state is funding huge amounts of training as well as intensive services. What are we receiving?
- How to balance family permanence with children's safety?
- How does adoption affect children's outcomes?
- What are the intended and unintended outcomes of the change to Community Based Flexible Supports (CBFS)? What happens to those people who are either discontinued from services or left waiting for services?
- How can we best support people in recovery in the workplace?
- Why are there so few minorities in peer services?
- There is a need for further research into health disparities, which cut across not only cultures but also diagnoses.
- What role does technology play? What do we obtain from technological advances?

Key Themes

Change needs to be studied when it occurs.

We need to look at the mechanisms DMH might use to connect research to what is happening on the ground. When services change, there are opportunities to study them, but those opportunities may be lost if no one takes advantage of them in a timely way.

Feedback loops are missing.

There is little feedback from researchers to the community. Academics talk mainly to each other and publish primarily in peer-reviewed journals that other stakeholders may not read. Providers agreed that any research DMH is funding should have an impact on services and require that prospective researchers explain how they are going to bring their results back to the community.

Providers felt that DMH should be examining the efficacy of the money that they spend. At the present time medically-based community researchers pursue their own projects. Centers of Excellence should be encouraged to seek grants that will provide information meaningful to the community, and to conduct research in partnership with the community. DMH should find ways to manage this dialogue. A day was held to present research to stakeholders in an attempt to bridge this gap, but relatively few providers attended.. We need to find ways of connecting and interacting that will be useful to all stakeholders.

Providers feel that they contribute data to the system but never see any results. Data should be presented so that all stakeholders can access it. The Metro Suburban Area is gathering data on housing, best practices, and employment and holds an Annual Quality Improvement Symposium. One participant suggested that an award be presented for the research project that contributes the most at a provider celebration or a separate provider research day.

Discussion and Recommendations

A wide variety of studies are being conducted in the Commonwealth by a large number of researchers, covering many topics related to mental illnesses, their psychosocial and pharmacological treatments, and recovery. This work is supported both by the Department of Mental Health and by innumerable other public and private funders. Researchers' agendas derive from a variety of sources, including follow-up on their own or others' previous studies; other work going on in their institutions; and the availability of funding to support specific research content. When they are consulted, both provider and consumer stakeholders can identify what kinds of research they consider most important. This is the first time that these stakeholders have been asked by the Department of Mental Health for their opinions regarding the research agenda. Thus, community stakeholders have had little influence on the agendas of researchers or on the prioritization of grant opportunities Commonwealth supported researchers should pursue.

Although consumers and providers are eager to learn about results of research that can directly influence policy and practice, there is currently a considerable disconnect between research on the one hand and policy and practice on the other. In fact, there are two levels of disconnect that this study has revealed: 1) in the realm of ideas, between the research that is being conducted and the

areas of interest stakeholders express; and 2), in the realm of ongoing communications between mental health researchers and the stakeholders in the mental health community.

Providers and consumers expressed considerable frustration that neither the policies governing service delivery nor the programs they operate seem to benefit from the results of research DMH is supporting. This is the first opportunity that they have had to express their ideas in setting the research agenda. Stakeholders usually do not learn about the results of research that is being done. In some cases that research is irrelevant to their concerns; however, in other cases, it is relevant but there is no consistent meaningful communication. Many participants in the focus groups believed strongly that if DMH is funding research studies, those studies should relate directly to issues "on the ground" in the Commonwealth. This issue takes on particular significance now, as the state is in the process of dramatically changing much of the mental health service system – including restructuring both the adult and child systems of care, through Community-Based Flexible Supports and the Children's Behavioral Health Initiative respectively, and the new procurement of the Emergency Service system. These potentially transformative changes merit careful study so that the state can evaluate their impacts on all stakeholders -- providers, consumers and family members -- and learn whether they require modification.

There are some important qualifications to this report. Our approach to sampling assured that participants had a wide variety of experiences, however,subgroups, such as consumers and family members who are homeless, deaf, or anorexic, are not sufficiently represented. Similarly, providers who do not have trade-group membership may be underrepresented. Lastly, people who choose to participate in focus groups may be a particularly motivated and resourceful group.

Thus, the identified research topics of interest for the future listed below are not presented as representative of *every topic* where there is intense consumer and family member interest.

Consumer consensus regarding a research agenda

Based on the results of the focus groups, stakeholders would like to see research institutions address the following areas (see below) and disseminate their research results and literature reviews.

- Employment
- Housing
- Access to care
- Physical health and wellness
- Criminal justice
- Juvenile Justice System
- Stigma
- Fragmentation of services and systems.
- Rehabilitation and recovery research

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  - The Center for Mental Health Services Research at the University of Massachusetts has several grants related to psychosocial services, usually in combination with health and wellness initiatives.
  - Peer services, including Parent Partners, are simultaneously one of the areas of greatest interest among stakeholders, an area of new service development and one of

the more difficult subjects to study. The lack of work on this topic represents a major gap between community concern and researchers' efforts.
    - Boston University's Center for Psychiatric Rehabilitation focuses on recovery and rehabilitation, and has ongoing research projects on WRAP and peer education, but has not yet disseminated work products.
- CMHSR is doing important research with Transition Age Youth and Parents of Youth and the Beth Israel/Deaconess COE is conducting important research on first episode psychosis in adolescents. The results of these and similar studies should inform DMH policy and practice and be shared with other agencies.
- The COEs and other researchers are doing considerable work on multicultural issues and disparities, as a result of a new performance requirement of the contract with DMH. The focus groups touched on this topic, which is clearly important to stakeholders.
- One means of connecting researchers with stakeholders on specific topics would be to support stakeholders in taking a lead in a grant application. DMH might:
    - Involve representative consumers and family members in meetings with those who are doing the research;
    - Identify a research topic that is meaningful to community stakeholders and draft an abstract of a proposal that DMH will support; and
    - Send the relevant RFP's to potentially interested researchers.

Recommendations

The following recommendations to DMH emerge from this study:

1. Research results need to be more widely disseminated to stakeholders on a routine basis; if copyright issues are problematic, researchers can at least circulate abstracts of their articles. Interested individuals could then follow up on the information.
2. Periodic facilitated discussions should take place among researchers and providers, and among researchers and consumers.
3. Finding ways of sharing information and facilitating communication should be seen as a system-wide responsibility, shared by researchers, consumers and their advocates, and providers.
4. DMH should assure that the COE's are aware of the findings in this report as well as other issues the Massachusetts public mental health system is confronting, and seek opportunities to study them.
5. DMH could play an even more active role in defining the research agendas of the COEs it is supporting. It could also require that they disseminate their findings widely within the state.
6. DMH could also request that each COE submit an action plan that addresses the interests of stakeholders as determined in the focus groups described in this report. Part of that action plan should describe how the COE will engage stakeholders in shaping researchers' priorities and participating in selected grant applications.
7. DMH might spread the responsibility for following research more broadly within the agency by involving, for example, medical directors and others in area offices. The Excel charts developed for this report could be shared with appropriate DMH staff, enabling the department to determine who might want to serve as the lead for each topic; those individuals could meet with key researchers.

In closing, we congratulate the Department of Mental Health for acknowledging that there are many stakeholders who have an interest in the research conducted within the Commonwealth, and we appreciate this opportunity to learn about those interests and provide DMH with this report. We also appreciate that the DMH supported COEs have requirements for Consumer Advisory Councils, Multicultural researchers, and Research Dissemination. We appreciate the CMHSR's effort to establish a Mental Health Agency Research Network, with the goal of enhancing participation in research and disseminating research findings to Massachusetts mental health agencies and other interested stakeholders.

Appendix I:
Mental Health Research Priorities - Focus Groups

Introduction

Purpose

The public does not often have a say in what gets researched. The Department of Mental Health believes it is important for consumers and other stakeholders of mental health services to participate in the development of the department's research agenda, especially in deciding what is important to study in the research DMH funds. As a result, DMH has retained Consumer Quality Initiatives and DMA Health Strategies to conduct a series of focus groups on the priorities for mental health research in the Commonwealth.

We're going to ask you to participate in a discussion about what problems are faced by people with mental health and substance abuse needs. After identifying the issues faced by this community, we will talk about how these might become research topics that should be a priority for mental health research groups.

What is "Research"?

Research is the planned process of collecting and analyzing information to increase our understanding of a topic under study.

There are lots of different kinds of research. Clinical research studies diseases and medications. Social Science research studies how people live in the work, such as poverty, and special needs of certain populations like children and the elderly.

How do researchers decide what to study?

- Identify a issue/problem/ that needs to be addressed/solved
- Find out what other people have learned about the problem
- Define a part or piece of the puzzle that they want to delve into
- Go forward with the research (write up a plan, get money to fund the research, etc.)

How does research affect our lives?

- Mental Health policies may be influenced by research

For example: CQI did some research about the needs of transition aged youth. Major gaps in services were identified. As a result, the state has set aside a large amount of money to work on solving those problems, and new philosophy.

Treatment interventions should be supported by "evidence" from research studies

Ground Rules:

We are going ask you some questions… write down your answers and discuss them. You will be identified as a participant in this session, but your name will not be identified with specific comments or suggestions you make. We will summarize the results of this focus group and the others we hold for DMH. These results will be presented back to DMH in a final report that summarizes all the groups and makes some suggestions for the future.

Focus Group Discussion Guide:

1) Opening question:

"What are some of the critical issues faced by people with serious mental health conditions (e.g., DMH clients) in Massachusetts?" [Hand out cards to write on]

- Be as broad or narrow as you want to be.
- Keep it short to give everyone a chance.

2) Set priorities for the discussion:

"Which of these problems do you feel are most important for studying?"
[One way of doing this is to give each person three stickers. Each person goes up to the easels and places a sticker by the three issues that are most important to them. It's easy then to identify which issues get the most votes.]

- What else is important to study?

3) Research topic development: (Discuss only the top [3?] problems)

- "What would you like to learn about this problem? Why?"

4) Wrap-up:

- Thanks for contributing to this important discussion….
- The problems and questions that we have discussed today will be shared with at least DMH and the COEs, and used to inform their research agendas.
- Distribute information about the Centers of Excellence

Appendix II:
Introduction for Provider Focus Group

Summary

The Department of Mental Health (DMH) believes it is important for consumers and other stakeholders of mental health services to be a part of the research process, especially in deciding what is important to study in the research that DMH funds. As a result, DMH has retained Consumer Quality Initiatives and DMA Health Strategies to conduct a series of focus groups on the priorities for mental health research in the Commonwealth.

For many years, DMH has funded research; the Department currently funds two research centers at the University of Massachusetts Medical School and Massachusetts Mental Health Center Public Psychiatry Division. These are known as the Commonwealth Research Centers (CRCs). Funds from these contracts directly support certain research activities on DMH services and they provide support for the Center to develop federal and other grant proposals for additional research topics. The goal is to advance the research in the Commonwealth and to provide support for services and other research topics that promote the public mental health system.

Activities to date

To gather input on the current research in Massachusetts, the team held two meetings with each of the CRCs to discuss their current research and future research plans. We also reviewed research at other Universities in Massachusetts and conducted a review of the research approved by the DMH IRB. While not exhaustive, these summaries allow us to provide some evidence of the scope and breadth of research activities in the Commonwealth.

DMA Health Strategies and Consumer Quality Initiatives held five focus groups with consumers, parents and young adults to obtain input on research topics that the CRCs should support. We are holding a focus group with provider representatives in early June. We will summarize the input we receive, the summary of current research and our recommendations in a report back to DMH in late June.

Provider Focus Group Questions

- Is your agency currently involved with services research, clinical trials or research on other areas of your operations? Are you involved with the CRCs?
- What topics do you believe are the most important for the Commonwealth to support at the CRCs?
- What is the role of research in the public mental health system and how should it be funded?
- Do you have any suggestions for improvement? What are some examples that you can think of where research has advanced clinical practice?

Appendix III:
Introduction for Consumer and Family Focus Groups

Introduction

Purpose

The public does not often have a say in what gets researched. The Department of Mental Health believes it is important for consumers and other stakeholders of mental health services to participate in the development of the department's research agenda, especially in deciding what is important to study in the research DMH funds. As a result, DMH has retained Consumer Quality Initiatives and DMA Health Strategies to conduct a series of focus groups on the priorities for mental health research in the Commonwealth.

We're going to ask you to participate in a discussion about what problems are faced by people with mental health and substance abuse needs. After identifying the issues faced by this community, we will talk about how these might become research topics that should be a priority for mental health research groups.

What is "Research"?

Research is the planned process of collecting and analyzing information to increase our understanding of a topic under study.

There are lots of different kinds of research. Clinical research studies diseases and medications. Social Science research studies how people live in the work, such as poverty, and special needs of certain populations like children and the elderly.

How do researchers decide what to study?

Identify an issue/problem/ that needs to be addressed/solved

- Find out what other people have learned about the problem
- Define a part or piece of the puzzle that they want to delve into
- Go forward with the research (write up a plan, get money to fund the research, etc.)

How does research affect our lives?

- Mental Health policies may be influenced by research

For example: CQI did some research about the needs of transition aged youth. Major gaps in services were identified. As a result, the state has set aside a large amount of money to work on solving those problems, and new philosophy.

Treatment interventions should be supported by "evidence" from research studies

Ground Rules:

We are going ask you some questions… write down your answers and discuss them. You may be identified as a participant in this session, but your name will not be identified with specific comments or suggestions you make. We will summarize the results of this focus group and the others we hold for DMH. These results will be presented back to DMH in a final report that summarizes all the groups and makes some suggestions for the future.

Focus Group Discussion Guide:

1) **Opening question:**

"What are some of the critical issues faced by people with serious mental health conditions (e.g., DMH clients) in Massachusetts?" [Hand out cards to write on]

- Be as broad or narrow as you want to be.
- Keep it short to give everyone a chance.

2) Set priorities for the discussion:

"Which of these problems do you feel are most important for studying?"
[One way of doing this is to give each person three stickers. Each person goes up to the easels and places a sticker by the three issues that are most important to them. It's easy then to identify which issues get the most votes.]

- **W**hat else is important to study?

***3) Research* topic *development:* (Discuss only the top [3?] problems)**

- "What would you like to learn about this problem? Why?"

4) Wrap-up:

- Thanks for contributing to this important discussion….
- The problems and questions that we have discussed today will be shared with… and used to ….
- Distribute information about the Centers of Excellence

Appendix IV:
Schedule of Focus Group meetings

CQI conducted 5 focus groups across Massachusetts with consumers or family members to learn about their priorities related to mental health research in the state. DMA conducted one focus group with providers across the state to learn about their priorities.

1) Western Mass. Consumers
   February 2, 2009
   Western Mass. Recovery Learning Community, Holyoke, MA
      13 participants attended

2) Parents of Youth with Serious Emotional Disorders
   February 9, 2009
   Wayside Youth & Family Support Network, Framingham, MA 01702
      2 parents were in attendance

3) MBHP Family Advisory Council Focus Group
   April 6, 2009
      7 parents were in attendance

4) Eastern Mass Consumers
   February 11, 2009
   Transformation Center, Roxbury, MA
      15 participants attended

5) Young Adult Consumers
   February 17, 2009
   Tatnuck Booksellers, Westborough, MA 01581
      12 young adults attended

6) Central Mass Consumers
   February 23, 2009
   Central Mass. Recovery Learning Community, Worcester, MA 01603
      6 participants attended

7) Providers
   June 3, 2009
   MHSACM, Natick, MA 01760
      Management from 6 provider agencies across the state attended

CQI and DMA also met with both centers of excellence to learn about their work and the focus of their research. Meetings were held with each center on 9/17/08 and a follow up meeting was held with the UMass Center of Excellence on 1/8/09.

Appendix V:
Mental Health Research in Massachusetts, University and Medical Centers

University	Research Center	Research Foci	Key Researchers	Website
BI/Deaconess Medical Center	**Commonwealth Research Center**	The biological basis of psychosis and the optimal treatment for severe mental illness.	Larry J. Seidman, Ph.D., Director	http://www.bidmc.org/Research/Departments/Psychiatry/CommonwealthResearchCenter.aspx
UMASS Medical School Department of Psychiatry	**Center for Mental Health Services Research**	the nature, structure, effectiveness, and regulations of services for individuals with mental health conditions, development and dissemination of knowledge to improve the lives of these individuals, their families, and other community members.	Carl E. Fulwiler, MD, PhD Acting Director	http://www.umassmed.edu/cmhsr/index.aspx?linkidentifier=id&itemid=77968
Assumption College	Dept. of Psychology	Children- aggression, depression PTSD	Leonard A. Doerfler	http://www.assumption.edu/media-sources/forums/index.php?showtopic=41
	Human and Rehab services	Structured exercise, Wellness Peer support	John Pelletier Tom McCarthey	http://www.assumption.edu/media-sources/forums/index.php?showtopic=99
Boston College	School of Social Work	Self-directed care (cash and counseling) Multi-ethnic, person centered	Kevin Mahoney Tara Earl	www.cashandcounseling.org
Boston University	Center for Psychiatric Rehabilitation	Recovery Peer Support Services Structured Psychoeducational treatment	Sally Rogers	http://www.bu.edu/cpr/

University	Research Center	Research Foci	Key Researchers	Website
	Public Health	Performance Measurement Peer Support PTSD- risk factors, computer assisted treatment	Sue Eisen	http://sph.bu.edu/index.php?option=com_sphdir&id=239&Itemid=340&INDEX=9547
	Social Work	Hoarding Post-Partum Depression	Gail Steketee Paris	www.bu.edu/ssw/research/index.shtml
	Center for Anxiety related disorders	Anxiety disorders CBT Smoking cessation Children and Adolescents	Otto, Barlow, Jill Ehrenreich	http://www.bu.edu/card/ https://htmldbprod.bc.edu/pls/htmldb/f?p=1128:3:4405519014777514::NO::P3_FACULTY_ID:582
	Dept. of Psychology	Children/Family adjustment	Martha Thompson	http://www.bu.edu/psych/
Brandeis University	Heller School for Social Policy and Management - Schneider Institute	Financing and costs Managed care Dual treatment	Constance Horgan Don Shepard	http://sihp.brandeis.edu/research_listing_PRJ_RAB
Harvard University	Judge Baker Children's Center	Science/Practice Gap Youth Depression Parents with MI Transition age youth	Bill Beardslee	http://www.jbcc.harvard.edu/research.htm
	School of Public Health	Guns and Suicide	David Hemenway	http://www.hsph.harvard.edu/research/hicrc/firearms-research/
	School of Social Medicine	Social integration in recovery from psychiatric disability Eating Disorders Children and violence	Norma Ware Anne Becker Felton Earls	http://ghsm.hms.harvard.edu/research/mental_health/
Mt. Holyoke	Dept of Psychology and Education	First person narratives	Gail Hornstein	http://www.mtholyoke.edu/acad/misc/profile/ghornste.shtml
Northeastern University	Institute for Urban Health Research, Sociology	Minority women emergency services	Hortenisa Amaro Alisa Lincoln	http://www.northeastern.edu/bouve/research/IUHR/research_activities.html

University	Research Center	Research Foci	Key Researchers	Website
Simmons College	Social Work	Longitudinal study - birth through adulthood	Helen Reinharz	http://www.simmons.edu/ssw/sls/
Smith College	School of Social Work - Center for Innovative Practice	Effect of managed care on family-based practice Clinicians of color First Episode psychosis-"Open Dialogue" communication	Phoebe Sessions Mary Olson Joyce Everett	http://www.smith.edu/ssw/admin/academics_cipcurrent.php#managed; www.smith.edu/ssw; http://www.rocktheboattraining.com/conference/mary-olson.html
Tufts University	Dept of Psychology Center for Cognitive Studies	Neuroscience and schizophrenia	Gina Kuperberg	http://ase.tufts.edu/cogstud/index.asp
UMass Medical	Center for Health Policy and Research	Employment Economics Health Information Technology	Alexis Henry Robin Clark Jay Himmelstein	http://www.umassmed.edu/chpr/EvaluationResearch.aspx?linkidentifier=id&itemid=61146
University of Massachusetts - Boston	Center for Survey Research	Transition to adulthood - stress and mental health		www.csr.umb.edu/projects.htm
	Institute for Community Inclusion	Employment Systems Change	Susan Foley	http://www.communityinclusion.org/
	Sociology	criminal justice housing	Stephanie Hartwell Russell Shutt	http://www.umb.edu/academics/cla/dept/sociology/

Medical Center	Research Center	Research Foci	Key Researchers	Website
Brigham and Women's Hospital	Department of Psychiatry	neuroscience and brain development population-based clinical trials psychiatry and medical care	Levkoff,	http://www.brighamandwomens.org/psychiatry/
	Dept of Epidemiology	Pharmacology, Antidepressant use, children and suicidality	Sebastian Schneeweiss	http://www.hsph.harvard.edu/faculty/sebastian-schneeweiss/
Cambridge Health Alliance	Center for Multicultural Mental Health Research	Disparities Latino/Asian Depression	Alegria	http://www.multiculturalmentalhealth.org/
	Department of Psychiatry	anxiety/depression mood disorders - depression and bipolar trauma recovery and resilience		http://www.challiance.org/psychiatry/psychiatry.shtml
Children's Hospital	Department of Psychiatry	Pediatric bipolar disorder depression in children	Weisz	http://www.childrenshospital.org/clinicalservices/Site1936/mainpageS1936P0.html?CFID=57659054&CFTOKEN=fefbc53361f1a487-8ADC00C7-CF2B-5C33-2D3438639B66EE69
BIDMC/MMHC	Commonwealth Research	pharmacological treatments early intervention and prevention of SMI (prodromal) (TAY) Family and cognitive supports in the above areas neurocognition	Larry Seidman	http://www.bidmc.org/Research/Departments/Psychiatry/CommonwealthResearchCenter.aspx
Massachusetts General Hospital	Behavioral Medicine	CBT	Safren	www2.massgeneral.org/bmed/research.htm
	Bipolar Clinic and	CBT and neuropsych		http://www.manicdepressive.o

Medical Center	Research Center	Research Foci	Key Researchers	Website
	Research Program	interventions for improvement in complex chronic care psychopharmacology		rg/
	Center for Mental Health and Media	Transition to college diagnosing teen depression		http://www.massgeneral.org/psychiatry/research/resourcelab.aspx?id=22
	Schizophrenia Research Center	CBT Psychopharmacology Genetics		www2.massgeneral.org/allpsych/schizophrenia
	Dept. of Psychiatry	Bipolar and Transition Age youth	Aude Henin	http://www.massgeneral.org/psychiatry/
McLean Psychiatric Hospital	Mailman Center	neuropharmacology neurogenetics natural products research		http://www.mclean.harvard.edu/research/mrc/
	Shervert Frasier RI Clinical Unit Based Research	medications for SMI, etc. genetics brain imaging		www.mclean.harvard.edu/research/bipolar
Tufts Medical Center	Department of Psychiatry	neurobiological basis of brain disorders depression in Asian primary care patients		http://www.tuftsmedicalcenter.org/OurServices/Psychiatry/default
Veteran's Affairs Hospital, Bedford,	Dept of Psychiatry	Employment Peer Support Dual Treatment		
Harvard U	Center for Developing Child	Child Mental Health Network: Connecting Science, Policy, and Practice in Child and Youth Mental Health	John Weisz	http://www.developingchild.harvard.edu/content/mental-health-network.html
UMass Memorial Medical Center	Child & Adolescent Psychiatry Division	Neuroimaging	Jean Frazier	http://www.umassmed.edu/psychiatry/candi/index.aspx

The Department of Mental Health's Centers of Excellence in Research

The BI/Deaconess' Commonwealth Research Center

The Commonwealth Research Center (CRC) was created in 1987 at the Massachusetts Mental Health Center (MMHC) by the Massachusetts Department of Mental Health (DMH) to address the need for cutting edge clinical research on schizophrenia and related psychotic disorders. In 1993, the DMH expanded its commitment to support clinical research by designating two Centers of Excellence. The CRC, with a focus on neurobiology and psychopharmacology, was awarded a six-year contract in research support. The CRC also provides a base of support for the researchers of the Harvard Department of Psychiatry located in the Southeast region of Massachusetts. In June 2005, the CRC and the rest of the MMHC Department of Psychiatry of HMS were transferred to the Beth Israel Deaconess Medical Center (BIDMC), also a HMS teaching hospital, and became the MMHC Public Psychiatry Division of the BIDMC. In May 2007, the CRC was again awarded the DMH grant through the BIDMC Department of Psychiatry.

In November 2002, Larry J. Seidman, Ph.D., became the Director of the CRC with a central goal to develop new knowledge about psychosis in order to reduce the significant morbidity associated with psychotic illnesses. The Center specifically focuses on research designed to further understand the underlying mechanisms and manifestations of psychotic illnesses and the optimal treatments for persons with severe and persistent mental illness. The CRC directs programs for the early intervention and prevention of psychotic disorders and is engaged in the ongoing development of additional studies and programs. The Center particularly emphasizes the early phases of psychotic illnesses (including the "prodromal" period before frank psychosis develops) in order to have the best opportunity to prevent or delay the onset of psychosis or to attenuate the symptoms and improve life style through early intervention. There is also a health and wellness program under the direction of David Henderson, M.D. of Massachusetts General Hospital at Massachusetts Mental Health Center. There is a multicultural research program to better understand racial and ethnic disparities in mental health care and ensure the research at the CRC includes a multicultural perspective and presence in the design and implementation of research projects. Finally, the CRC disseminates current research findings from the literature and CRC projects to DMH providers and consumers to assist in the delivery of evidence-based clinical care through written abstracts from the literature, workshops and clinical conferences.

The current CRC leadership works closely with several advisory committees including a Consumer/Family Advisory Board in collaboration with Consumer Quality Initiatives, Inc.; the Harvard Medical School (HMS) Psychiatry Executive Committee Board of Advisors; and a Scientific Advisory Board made up of a number of senior facultiy from several HMS-affiliated hospitals. **For more information abou the Commonwealth Research Center, go to: http://www.bidmc.org/Research/Departments/Psychiatry/CommonwealthResearchCenter. To review the 2009 Annual report, go to: http://www.bidmc.org/Research/Departments/Psychiatry/CommonwealthResearchCenter/AnnualReport.**

The University of Massachusetts Center for Mental Health Services Research

The Center for Mental Health Services Research conducts research to enhance services, improve the quality of life, and promote recovery for people with behavioral health conditions. Founded in 1993 as a Massachusetts Department of Mental Health Center of Excellence at the University of Massachusetts Medical School, we have internationally recognized expertise in program development, services research, quantitative and qualitative research methods as well as wellness, forensic/legal issues, child and family mental health issues, transitional youth, human rights issues, co-occurring disorders, and epidemiology. Our 19 faculty and 24 research staff are committed to translational research, and work closely with consumers, providers, family members, and administrators to design and conduct research, share findings, and disseminate information with the real world recipients of policies and services.

Mission & Goals

Mission: To be an internally recognized academic center that conducts research on the nature, structure, effectiveness, and regulations of services for individuals with mental health conditions, and develops and disseminates knowledge to improve the lives of these individuals, their families, and other community members.

Goals:

- To conduct research and develop knowledge to:
  - Improve services for people with mental health conditions
  - Improve the quality of life and promote the recovery of people with or at risk of mental health conditions, and their families.
- To disseminate knowledge through a range of activities that include teaching, publishing, speaking, consulting, and training.

To learn more about the Center for Mental Health Services Research, go to:

http://www.umassmed.edu/cmhsr/index

To review the Center's 2009 Annual Report, go to: http://www.umassmed.edu/cmhsr/annual_report